CHAPTER FOUR

THE CIRCULAR MOVEMENT IN THE PROCESS OF INTEGRATING HEARD STORIES AND LISTENING TO NEW STORIES

In the previous chapter, I brought other voices into the conversation: voices of literature and others. Discourses were unpacked to come to an understanding what is said about adolescents, what they say about themselves, but also to understand the influence their context, their environment and their culture have on them.

A main focus of this chapter will be to integrate these different voices and to bring them into conversation with one another. The aim is to come to a new understanding of the research journey so far.

I also want to listen to other important voices that were not listened to before. These are different voices, apart from the young people themselves and other role players in the inner city regarding care.

1. OTHER STORIES OF YOUNG PEOPLE IN SOUTH AFRICA

The primary group I worked with is not necessarily HIV positive. The fact that the study is named "adolescents infected and/or affected by HIV/AIDS" makes it possible for me to specifically listen to voices of young people infected with AIDS. I chose these two stories, because they resonate with stories I have previously heard about experiences of people living in the inner city.

Personal stories of young people in South Africa (www.avert.org):

I am a 24 year old female youth. At the young age of 10, I was being babysat by my best friend's cousin and ended up getting brutally raped several times that evening. Two years after the rape we were finally able to prosecute the guy and get him incarcerated for a short term of only 3 years. Within 3 months of the start of his incarceration, my mom got a visit from the local health department saying that the guy who raped me tested + for the HIV virus; and that it would be a good idea for me to find out. Well a couple weeks went by and I got the bombshell dropped on me. My test also came back + when I was 12 years old. Because of the lack of knowledge about the virus I ended up getting forced out of high school, because they didn't want it in their community. I have since got my GED and Bookkeeping degree and I was able to pick up and prove everyone wrong. I am a proud mom of a 6 year old NEGATIVE child. Good luck to all!

-----Ralina 24

These and many other stories of young people who are positive, contributes to my understanding of how young people experience HIV/AIDS and care. The hurt of being excluded and stigmatized is very real. People in South Africa are still very much "HIV negative" (Chapter 2, Session 6).

2. LISTENING TO THE STORIES OF CARE INSTITUTIONS AND HOW YOUNG PEOPLE EXPERIENCED IT

The accessibility of clinics for services regarding HIV/AIDS is not simple at all. The private doctors charge R180 to conduct a HIV test. After lots of negotiation, you can get a bargain at R100.

The public clinics do the testing for free, but that is an absolute challenge. I went through the process with 6 of the group members (Miranda, Thabogo, Precious, Ronald, Jerry and Louis). It was a terrible ordeal! For them and for me. I took them on a day during the school holiday, because the clinic is only open till 14:00 during the week. This time is out of the school going learner's timeframe, because school only closes at 14:00. We came to the clinic at 8:00 in the morning when they opened. You get a number and sit in the queue of the AIDS-test department (which was already embarrassing to the teens).

We waited for 2 hours before each one was called into a separate booth. The pre-test counselling is done in a very mechanical way. The children are asked in detail about their sexual lifestyle. This was very embarrassing to them. The test gets done and then they must return in a week's time and collect the results.

In my discussion with the group who went for the testing, they expressed their utter humiliation in this whole experience. The one boy, who has homosexual preferences felt extremely vulnerable and after the testing experience left our discussion group as well. There was not an opportunity to speak to him, but I wonder if he just didn't have the courage to face the group again after knowing his status.

3. DISCUSSIONS WITH THE SEDIBA HOPE AIDS CENTER PERSONNEL

In sharing these experiences, I will not try to claim scientific facts. This is the experience of the personnel working in the centre. It can be disputed by other

people's experiences. I will not try to make this universally applicable. This is the experiences regarding a specific inner city AIDS centre.

Kgabo Mmekwa is the coordinator of the project. The centre started during the same time that the group sessions were held (2002). It is a partnership project between PEN, PCM (Pretoria Community Ministries), Wesley Methodist Mission, St Andrews Anglican Cathedraland CMR (Christelike Maatskaplike Raad). The need of the young people to have access to information about health, sex and AIDS as well as access to proper medical care, was a strong motivation for the launch of the centre.

The teenagers in all of PEN's ministries have direct and free access to the centre and make well use of the service. It is also open to all the inhabitants of the inner city. Youth hostels are in the direct vicinity, the National Defence Force has offices next to the centre. People living on the streets of the inner city; use the services of the centre at no charge.

This is some of the valuable insights Kgabo shared with me:

The youngest teenagers that come for services to the clinic are about 13. They make use of the pregnancy tests, HIV tests, contraception, sexual transmitted diseases (STD's), etc.

There are three groups of young people that are served within their different areas of need: the very young teenagers between 13 and 16 years come mostly for pregnancy tests and sex education. The girls often come for pregnancy tests and contraception. This group is targeted for basic sex education. If they come for HIV treatment or STD's, it is mostly as the result of an abusive relationship with an adult. It usually involves single mothers with a boyfriend who abuses them, or a stepfather.

• The next group is **the age group between 16 and 19 years**. These young people are just awakening sexually. Most of them are only starting to experience with sex. Their experience is usually occasional and not with a whole lot of different partners. These once off encounters can often result in pregnancy. Young people who do become HIV positive in this age group are often abuse-related, or these young people are involved in prostitution.

There is not a big quantity of young people in this age group who become HIV positive. The group that was involved as co-researchers fell mostly in the first two age groups. As far as I know, not one of them was HIV positive, although all of them were affected by HIV. This bothered me at first, because I wondered about the validity of the theme of my research project. This discussion with Kgabo, helped me to think about this.

According to her experience, this is a very vulnerable age group and actually a group on which a lot of our time and effort should be spent regarding prevention. These young people are starting to make important life choices about their own values and lifestyle. They are mostly not infected with sexual diseases yet. They are only starting to experiment sexually with young people who are in their own age group and who are also not infected yet.

If we can spend a lot of time on building relationships with our young people, teaching them about sex and helping them to find language to express themselves, it might help them to make more educated choices. In my casual discussions with the young people in general, I realized that everybody motivates young people to save themselves sexually for marriage. The sad thing is that nobody that I know talk to young people about the place of sex in marriage. The perception created by the media,

that sex is very important is never realistically put into the perspective of marriage life.

This might be another topic for further research: the communication about the role sex ought to play and plays in married life. My impression is that young people not have a picture of the beauty of building a long term love relationship through sex for a married couple. I agree that this picture might not be true to many people, but I think it needs to be explored further.

This group often does not come for help to the professional help agencies, either because they do not know how to ask for help or they do not know what language to use. Kgabo thinks it is the latter. They sometimes think their parents are the whole world. They do not know that they can ask for help outside of their families. Often these young people are too afraid to tell on their parents or on their family. They are deeply loyal to the parents and very afraid to cause trouble for them. The adult world can be a scary place for these young teenagers.

It is interesting that these teenagers don't think about their future much. They live for today. Their parents force them to go to school. They make their lifestyle choices, not based on their dreams for themselves, but often according to what the moment brings.

There is also a difference between the type of aid needed between the black teenagers and the white teenagers. The white teenagers mostly get infected through their drug habits – infected needles, etc. The black teenagers get infected through their sexual contact.

Then lastly there is the older adolescent which is in the age group of
 19 to 21 years. These young people are more informed about sex and

the risks. They mostly become infected because of their lifestyles. Their main causes for using the service of the centre, is for the girls, being scared because they had a condom burst, and for the boys, because they had sex without using a condom (mostly because of an "emergency").

What is interesting about this group is that they often come to be tested for HIV before going for a job interview. They assume that they will not be employed if they are HIV positive, or that the future employer has a right to know their status.

The young people in all of the age groups are daily confronted with the possibility of being raped: male and female. This fear is a reality in all three groups. This fear was confirmed by the reflection groups.

4. FEEDBACK FROM THE REFLECTION TEAMS

4.1 Reflection team 1

On the 12th of September 2004 I held a reflection group with a group of teenagers from Salvokop (a very poor community close to the Pretoria Central Correctional service). I used my reflections from Chapter 2 and the closing remarks in the same chapter to lead me in the discussions. I invited them to reflect on these remarks and share how they experience some of the issues. I did the same with the group who participated in the original group. Some of them have left school, but those who remained participated.

The Salvokop group were the following: Mpho Matabane, Assya Ngola, Merriam Mmachalca, Thandi Mahlangu, Bianca Olifant, Relaine Titus, Kgothatso Padi, Portia Monyai, Alta Long and Jane Selwangana.

I did not use the personal stories of the group members as part of the reflection, because we did not agree to this previously and the young people know each other.

The first impression I had from this group, was that they do not know people who are HIV positive. This might be because I do not know them well and they do not feel comfortable enough with me to share what seems like intimate stories, or they live in an environment where people do not share their status openly, or people are not HIV positive in their area. Most of the other experiences we talked about, using my reflections as a guide in the discussion, were confirmation of what I wrote in my previous reflections.

We started of with them talking about the openness they feel to talk about HIV/AIDS. The distinction was made when I asked them if they felt the same openness to talk about sex, which they do not feel. It is easier to talk about a disease that is apparently far away and not touching their daily life. The moment we talked about how they would feel if they were HIV positive, it was quite different. Immediately they identified with the expressed stereo typical image of people who are HIV positive. They expressed their own fears of being rejected by their friends. Their biggest fear was not to be rejected by their families, but their friends.

Maybe for the first time I realized that there is a big difference for the young people to talk about sex and to talk about HIV/AIDS. It is easier for them to talk about AIDS than sex, especially if you are not HIV positive.

We confirmed the definite tension in their families about choosing care from traditional healers, or from modern medicine. It was interesting that they expressed fear of traditional healers and fear of coming into conflict with their families for rather choosing modern medicine. Other opinions also were that the

traditional healers were effective, in specific illnesses. The specific illnesses would be spirit-related illnesses.

I was again confronted with basic questions about HIV/AIDS, like where does it come from and how do you deal with sex, to not get pregnant. We talked about pressures they experience to become sexually active. We also talked about their real fears of getting raped – not only by strangers, but by their friends.

They shared their own horror stories of having to go to a government hospital for care: how they are abused by hospital personnel, how they are treated like **the poor** who can't afford better care. They told stories of being treated by doctors who scowl and swear at them for being so stupid to get sexually active, or scowled at them because they waste the doctor's time with such unimportant problems.

This was very upsetting to me. People, who are forced to sit in long rows and wait to be treated because they can not afford better care, get abused by the personnel as well. They expressed their horror at thinking they have to go to a clinic for any medical care: not even talking about sensitive issues such as sexual transmitted diseases or teenage pregnancy.

4.2 Reflection team 2

On the 15th of September 2004 I invited the group members that were part of the initial group to attend a reflection session. I also invited new people to attend this session. Twenty young people came to the session. We recommitted to learn the drama that the original group started with. Every one was very excited about the possibility. There were 6 members of the original group present.

The same content was discussed than with the firs reflection team. Similar opinions were shared about most of the content. What was different to this group, was their experience about knowing people who are HIV positive. They

expressed immense dissatisfaction with medical care that is available to them. Most of them shared stories of humiliation by nursing staff at the local hospitals through talking down to them, asking them embarrassing questions if they go for any sex related treatment. They told stories of being scowled as "bitches" if they ask for any contraceptive medication. Pregnant young people get physically abused and humiliated. They get hit on their legs and told to open up like they did when they had sex. They tell these stories with the utmost horror.

Some of the girls spoke about the occasion when I took them to the clinic to get tested for HIV. They think back on that experience as some of the scariest experiences they ever had (contrasting with their lives of fear in the town ships). They remembered how it felt, having to face an adult that must give them the verdict of HIV positive or negative. That was scary in itself. Miranda remembered that she felt uncomfortable playing in the drama. She had the role of the girlfriend who was rejected. She felt as if people will reject her in real life because she is associated with the drama about HIV.

5. VOICES IN MY HEAD AND AIDS IN MY FACE

5.1 My understanding of the church and my own challenge

The challenge facing young people infected and/or affected by HIV/AIDS, living in the inner city of Pretoria, especially formulated out of the different sessions with the teenagers will be discussed.

Young people definitely form a target group to the church to do any prevention work with, regarding AIDS. Inner city realities like violence in the community, violent family lives, globalization that ends in different moral values from those of their families and inaccessible health services enhance their vulnerability to be infected.

I am convinced that the church (and I) can do more:

- Take an advocative role in ensuring young people get accessible health care which are their legal right
- Make the church a friendlier place for young people where they will find friends to whom they can talk to about sex and about AIDS
- Get more structures in place to help care givers to become more present in the world of young people
- Make care centres where I have an influence, a youth friendly place
- Keep formulating theology of care and inclusive theology for young people.

5.2 An African world-view meeting globalization

I have spent time on trying to understand the implications of an African world-view. The influence of globalization on this specific group was discussed in some of the group sessions. I now want to explain what I understand under globalization and how this world-view is influencing children living in the inner city.

5.2.1 Globalization in the inner city of Pretoria

Meylahn (2003) did an intensive study on the influence of the Global village in an urban context. He shares many stories of how globalization affects individual stories and community stories. Meylahn (2003:19) gives a clear description of globalization: "Globalization is the process by which the world is becoming ever smaller and more connected into a global village. This is a process determined by global markets, global finance markets and global communication networks." He further explains that the global village is an exclusive village, excluding people who are not economically able (e.g. jobless people) or excluding people who can not access the communication and information networks.

He shares his story of his inner city experience in relation to globalization (2003:164): "In the inner city one could see that the group areas act was no

longer in place. The people living in the flats were no longer white only; the people selling goods on the pavements were mainly black hawkers and foreigners. Pretoria was changing in to a global African City. This idea was exiting to some but certainly not to all as numerous people wanted to get out of The churches had similar ideas. As their the city and move to the suburbs. members moved out to the suburbs they felt the need to move out after them. The inner city started to become a no go zone for many who lived in the suburbs. Many saw the inner city as a place of crime and overcrowding. inner city, as I experienced it, is a place of suffering and poverty. It is a place where homeless and unemployed individuals try and make a living form the scraps of society, where economic and political refugees seek a living for themselves, where hawkers try and earn some money to feed their families, where teenagers flee from their families and social conditions only to end up in prostitution and drugs. It is a place of brokenness, where people try to construct and reconstruct their lives on the margins of society with the broken bits that society throws to them."

There are many stories to be told about the inner city of Pretoria. This view of the influence of globalization is one specific view.

5.2.2 Young people experiencing globalization

The young people expressed confusion caused by globalization. Conflicting values that are presented by the media about sex (Chapter 2, Session 3). For instance values that promote sex with multiple partners as the going norm. Individuality as an accomplishment. The Hollywood image of family life – divorce, broken relationships and easy love. The picture of empty, shallow relationships, painted with care. Opposed to the American dream of having everything material that brings success and admiration. It is preached that money is everything and ambition is the key.

These values are in conflict with many of the traditional values from within the African context.

5.2.3 Is it love at first sight, or will it end in divorce?

I do not know the answer. I can only describe the confusion that these different world-views bring into young people's lives that must make every day choices about very important issues. They struggle with conflicting world-views and conflicting value system.

Maybe there is an analogue in the story of HIV/AIDS and care, and that of different world-views. The African world-view witnesses to shared community and people who belong to something. It witnesses to communities who collectively share the burden of illness and who celebrate healing. It tells of communities who stand together, cry together and laugh together.

HIV/AIDS narratives witness of people being isolated and ostracized. People who are HIV positive get to carry the burden alone. Communities become HIV negative, because one individual became HIV positive.

A person next to some one who is HIV positive is seen by others as a person with AIDS in his and her face (Chapter 2, Session 6). To be merely associated with some one who is HIV positive is to be stereotyped and isolated.

HIV/AIDS witness to stories of the absolute opposite than stories of an African world-view. Maybe views that HIV/AIDS is a Western illness (as voiced by the group- Chapter 2, Session 3) are not so strange after all. HIV/AIDS absolutely does not fit into the African world-view about care.

5.3 I see AIDS in my face, but who cares?

All the time I feel myself identifying more and more with young people and their quest to stay positive (Chapter 2, Session 3). I try to understand how they experience care. I hear their voices about neglect and being let down by the adult world in not providing the care they need and have a legal right to. The

research has taught me a great deal about care through the eyes and the voices of the young people.

5.3.1 Care narratives

5.3.1.1 Weingarten

Weingarten (2001:1-12) shares her life story of her own illness and that of her daughters. She describes her illness narratives in these following ways:

- Coherence, closure and interdependence narratives
- Restitution, chaos and quest narratives
- Stability, progressive and regressive narratives.

5.3.1.2 Pienaar

Pienaar (2003:4.2) describes care in terms of:

- · Empowering care
- Burdensome care and
- Meaningful and rewarding care.

5.3.1.3 Baart

Baart (2003:151-154) wrote a model of good care out of his participation in the broader SANPAD project. He describes good care in four phases:

Caring about

This is where the care giver "tries to open up and allow myself to be drawn into the life world of the other".

The question to ask: "one should find out where to look".

The quality involved: "attentiveness (so that what needs attention in reality may penetrate one's consciousness.)"

The theological motive: "election (the suffering one is heard, seen, picked out and I am going to care about him/her."

Taking Care

"A crucial activity here is the establishment of a relation in which the needy (looking for care) person can become visible as(s)he is – ashamed, stupid, longing, terrified, guilty, strong, addicted, self-conscious, etc.

<u>Important questions</u>: **Who** are you? How you want me to know you? What are you telling and asking me?

The quality involved: "In this process of mutual disclosure it may become clear what I can do or be for you, and I have to decide if I am willing to do so and accept the implied **responsibility**."

<u>The theological motive</u>: relation – "I choose the leftover places in your biographical context: if you want to, consider and treat me as your brother, your friend, your mother."

Care Giving

"..the practical carrying out. Her the offer of care is made and in that offer I am present with my energy, invention, affects, emotions, skills, morality, reflection, and it is up to you to use them."

Question to ask: "What is done and how it is done?

The quality involved: "Besides the appropriate offer (what), I am expected to act competently".

<u>Theological motive</u>: "...the service of love and compassion".

Care Receiving

"..care is completed by asking for feedback, evaluating the meaning and effects of the care and eventually adjusting it."

The question to ask: "One should reflect on the **how** and not go on without a sound insight into it."

<u>The quality involved:</u> "...depends on the **responsiveness** of the carer and thus on the continued relationship after the care-giving."

<u>Theological motive:</u> "...we may interpret this stage of care – the after-phase of the giving – as the humble art of receiving and accepting, the change of roles."

In discussing this model, Baart (2003:152) explains that care is "complex" and "multi-layered". This model to me is a great instrument to grasp this complex challenge of understanding care, in the end to be able to provide better care.

These writers have motivated me to venture to describe care narratives as I have discovered it in my research journey.

5.3.2 Care narratives developed from this research

5.3.2.1 Fearful care

Young people experiencing absolute anxiety in the mere thought of having to go for medical treatment to "care" institutions. This formal care instilled fear in young people to go to any clinic or hospital. Fearful care was confirmed by both the noted reflection teams. There is an aspect of fearful care to be described by teenagers living in abusive relationships as well.

5.3.2.2 Paralyzing care

I have heard about stories of care that paralyze people and make them victims of their illness: people who are stripped of their right to care and of their right to being acknowledged as a person, young girls chased away by their families because they are pregnant, young people who are abused and paralyzed into silence and pain. Teenagers often don't have the language to ask for help.

5.3.2.3 Legal care

In my research I have come to the discovery that it is the legal right of a child to be cared for. How this right must be claimed, is still uncertain. Maybe by starting to name it as a legal right of children, some people might be moved to action. These care narratives must be communicated especially to power structures like government and formal health care institutions.

5.3.2.4 Nurturing care

I took the group to visit a care facility for HIV positive children. One of the guys, who never were very talkative in the group, had this wonderful encounter. A nurse at the centre gave him a baby who was very ill to hold. Having seen Isac for the very first time in his life, holding this HIV positive baby, not wanting to let the baby go because it might die if he does, have made a very deep impression on me. There is a capacity for nurturing care in young people that need to be explored and developed. He vowed to become more involved with children in general, because he discovered a deep love for children during this experience. I am convinced that there is a lot of development to be done through intergenerational care.

5.3.2.5 Communal care

In this research so far, I have learned a lot about care that is deeply rooted in especially the African culture. I have learned of a communal understanding of healing and illness. A flame of hope was lighted in me through shared horizons with people who experience this communal care. Many stories are told of families who care for extended family members, or children of friends who are destitute. I am also motivated to search for communal care narratives in my own Afrikaner culture. This metaphor for care invites a reinterpreting of the understanding of shared "community" in the theological sense: that there are possibilities in the ritual of community that can be explored to express a shared experience. The ritual of community can create space for deconstructing the horrors of people living with HIV/ÁIDS: as being a ritual of inclusion, of celebration and of shared pain.

5.3.2.6 Present care

My own thinking about care resonates with narratives of caring people merely showing up and who are just there where they are needed. This journey with the young people has inspired me to spend more time trying to live in this narrative with a new commitment. Baart (2003:137) explains this narrative about care as follows: "A characteristic that they (neighbourhood pastoral ministers) have in common is that they are there of others without focusing directly on problem solving. Problem solving can indeed emerge from their efforts, but that is not their overt intention. The most important thing these pastoral ministers bring to the situation is the faithful offering of themselves: being there, making themselves available, coming along to visit and listen, drinking coffee together or sharing a meal, completing a small household project, running errands, accompanying patients on a visit to the doctor, going for a walk with them, visiting a grave site, sending a birthday card, playing together on the street, being there when a child takes her final swimming test."....."Instead, the focus goes to the cultivation of caring relationships, and the approach is deemed successful even when there is no evidence of concrete problems being solved."

Not knowing what the answers are in many difficult situations and in sharing people's stories of stuck ness, I have come to appreciate the narrative of a caring presence even more. In my own experience of care, this has been very meaningful to me, when people care for me by merely being there when needed.

5.3.2.7 Advocative care

The young people in my group have invented and storied this narrative. Their fierce commitment to advocate about HIV/AIDS will stay with me always. I was always touched by their enthusiasm and dedication. They became the experts on sharing their stories insight regarding HIV/AIDS. This was confirmed to me through my informal discussions with group members now, a year later. Most of them are still inspired to keep doing this.

5.3.2.8 Storying care

Through the narrative approach, people are experiencing the power of storying care. The share of stories bring restorying and retelling and reinterpreting of old worn out stories. In sharing restoried stories, new stories are written and lived in. In the group I experienced the power of shared stories. It unites a group of strangers into a new healing community. Freedman and Combs (1996: 100) writes about the development of a history of the present. "...once a preferred event has been identified, we want to link that event to other preferred events across time, so that their meanings survive, and so that the events and their meanings can thicken a person's narrative in preferred ways. Therefore, once a preferred event is identified and storied we ask questions that might link it to other events in the pas and the future." To take the time for storying care, alternative stories are recorded and given privilege above stories of stuck ness. To open space for stories, is an important part of caring.

6. COLLECTING MY THOUGHTS

There are still much more to be said about care and about adolescents' experiences of care. These are a short collection of what I have learned together with the young people in my group and through the journey of my research.

6.1 New places of understanding:

Hearing young people's voices, being infected with AIDS, brought the reality of rape, a culture of violence in South Africa, isolation of people living with AIDS and the family pain of young people infected to the fore.

- Understanding the reality of how inaccessible health care and other ways of care are for young people is a disturbing experience for me
- Listening to Kgabo, I was again moved by the urgency of every care giver to succeed in providing care to our very vulnerable but very special group of young people
- The absolute horror and reality of family abuse, child molestation and rape is heartbreaking

- The big opportunity of journeying with young people in making responsible life choices is very important
- Understanding the potential of utilizing an African world-view and African culture in search of new solutions to provide care is a new journey for me to embark on
- The hidden power (and maybe unique outcome) of community involvement in providing holistic care, needs serious attention
- Care in its broader understanding, needs to be made accessible for young people
- Young people need to become much more involved in the action of care.
 They need to be consulted as experts; they need to be trusted with e.g.
 the responsibility of advocacy and nurturing in new ways.

7. IN CLOSING

It is an important place in the research journey to take a moment to look back on the journey and to look forward to some form of closure. In myself, I start to ask questions like: was it worthwhile, did I come to new understanding, how is this making a difference in the world of young people, who are benefiting from this, and what were the sparkling moments of this journey?

This phase of further developing the research story brought me to new places I has not been before. Listening to other voices surrounding young people, I did take courage in what is being done for the inner city teenagers. To me it is encouraging to know there is a clinic in the inner city where young people can go to ask questions, to tell stories and to be cared for physically.

In the next chapter I shall further reflect on these questions and try to come to some understanding or maybe just new formulated questions.